

**Grant Number:** 5T15AI07551-02

**PI Name:** FISHER, CELIA B.

**Project Title:** ETHICS COURSE ON SCIENTIST-PARTICIPANT PARTNERSHIPS

**Description:**

The primary goal of this project is to develop, conduct, evaluate, and broadly disseminate a series of short-term ethics courses for researchers and students, institutional and program administrators, and members of institutional review boards in academic and health care settings. The pedagogical aim of the workshops is to provide attendees with knowledge and skills that will enhance their ability to identify and address ethical, legal, and social issues in research and to encourage them to seek and incorporate the opinions of prospective research participants from socio-economically and culturally diverse populations into ethical decision-making practices. To date, six workshops have been developed featuring lectures by noted scholars, written materials, case discussions, and dialogue with community members. Case studies are individually tailored to the research needs of each audience and are designed to draw attention to how community perspectives, especially the perspectives of participants and family members from ethnically and economically diverse populations view research ethics practices. Each workshop covers: (1) the history and role of institutional review boards; (2) types of research that qualify for exempt or expedited review; (3) maximizing research benefits and reducing risk, with emphasis on RCTs, the concept of clinical equipoise, and challenge and medication discontinuation designs; (4) informed consent procedures, including special issues associated with child and adolescent participants, adults with impaired capacity to consent, and federal guidelines for emergency research consent waivers; (5) confidentiality procedures including ethical issues associated with genetic testing, HIV/AIDS related research, and use of the Certificate of Confidentiality. A seventh workshop has been developed that focuses on the ethics of mentoring faculty-student research collaborations.

A second aim of the project is to support and encourage empirical work on ethical procedures through the award of \$1,000 - \$2,000 scholarships for quantitative or qualitative research designed to improve ethical practices using prospective participant perspectives. Five such scholarships have been awarded to researchers who are investigating the following issues: (1) informed consent as an interactive process with Asian American high school students and their parents; (2) improving parental consent, patient assent, and debriefing procedures in research with ethnic minority adolescent psychiatric patients; (3) consent, confidentiality, and debriefing procedures in dating violence research with undergraduate students; (4) participant reactions to research procedures examining beliefs surrounding interracial couples in American society; and (5) adolescent and parental perspectives on the risks and benefits of research on teenage drug use.

A third aim of the project is to disseminate information to a broader audience. In this regard, a web site has been constructed that provides links to federal guidelines and examples of case studies utilized in the workshops. In addition, the PI has written articles on preparing successful proposals for IRB review that have appeared in the American Psychological Association's Psychological Science Agenda and the Society for Research in Child Development Newsletter.

A final aim of the project is short-term and long-term evaluation of the impact of the workshops on participant knowledge and activities. Short term evaluation is conducted following every workshop with a series of Likert-type questions addressing (1) satisfaction with the clarity and format of workshop materials and presentations, (2) the degree to which workshops enhanced knowledge of different aspects of ethics-in-science decision-making; and (3) and the extent to which participants would be more likely to engage community members in dialogue when designing ethical procedures. Long-term evaluation will include follow-up surveys with workshop participants regarding the extent to which the ethics course increased their involvement in ethics related research, IRB participation, and improved their ability to identify and resolve ethical issues.

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